

Better disaster support needed for disabled kids

By Sayuri Nitani
Yomiuri Shimbun Staff Writer

Three months have passed since Kumamoto Prefecture and its surrounding areas were jolted by earthquakes, a disaster that forced the evacuation of severely disabled children, including those who receive at-home care such as respirators.

What kind of responses are needed to protect such children during times of disaster? The experiences of a nonprofit organization active in the disaster zone could help shed light on the issue.

"It's a relief to be back at home," said Akari Nishida, 45, of Nishi Ward, Kumamoto. Nishida's eldest daughter, 9-year-old Nachika, has cerebral palsy. She uses a feeding tube to get her nutrition, as well as a special machine that helps remove phlegm.

After the major quake on April 16, the family evacuated to Nachika's special needs school because they were worried about aftershocks. They were also concerned that prolonged outages and contamination of water could lead to hygiene issues like difficulties cleaning Nachika's respirator.

As Nishida and her family carried on with their evacuee life, she received a message on her smartphone asking if her daughter was safe from Saori Nakamoto, a nurse at a home-visit nursing station called Step Kids who often handles

phlegm removal and other care.

Step Kids is operated by NEXTEP, an NPO registered in Koshi, Kumamoto Prefecture, which sends nurses to the homes of children in seven municipalities in the northern part of the prefecture.

Nursing staff made sure children and families were safe before resuming nursing visits three days after the major quake struck. Relieved at the news, many families like the Nishidas were able to return home.

Support at the ready

The nursing station was able to swiftly provide children with support because it is well-prepared on a routine basis — Kumamoto Prefecture sees two or three typhoons a year.

It is crucial for disabled children to have continuous care, particularly during power outages for those using equipment like respirators. When a typhoon is coming, the nursing station already has measures in place such as admitting disabled children into hospitals ahead of time.

During the Kumamoto quakes, Nakamoto and other staff used the Line chat app to check if children were safe after the foreshock on April 14 since the phone lines were down. That same day, two children using respirators were evacuated to hospitals. After the main quake, six children were im-

mediately admitted to hospitals.

"It was good that both the parents and staff had training so they knew what to do, and we were quickly able to confirm everyone's status using the internet," Nakamoto said.

But support was not available for all the children who needed it.

"There were children who couldn't go to evacuation centers because they thought they might be a disturbance to those around them or there were fears of infectious diseases," said Tomoyuki Shimazu, head of NEXTEP and a pediatrician. "There were also children who only visited as outpatients more than a month after the earthquakes."

Raising public awareness

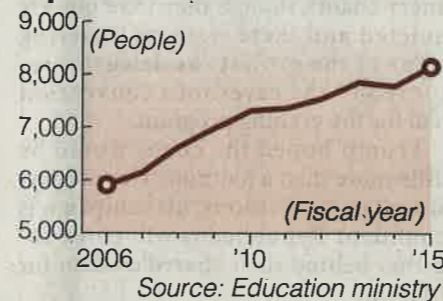
With medical advances, an increasing number of children are receiving at-home care such as respirators and feeding tubes.

According to the Education, Culture, Sports, Science and Technology Ministry, students at special-needs schools requiring medical care rose from 5,901 in fiscal 2006 to 8,143 in fiscal 2015. Among them, 5,935 traveled daily from home to school while 1,180 were on home-visit programs.

The 2011 Great East Japan Earthquake struck partway through the rising trend. Many children struggled while living as evacuees.

"There were lots of children who had to stay in their homes since they

Rising number of children who need medical care at special-needs schools



couldn't go to evacuation centers over concerns about the noise the machines make, or hospitals turned them away," said Yuichi Takeyama, director of Alive Ltd., a Sendai-based home medical equipment supplier that continues to deliver oxygen tanks to children using respirators who live in disaster zones.

These experiences spurred initiatives around Japan to protect children when disasters strike.

The Yokohama-based "Network to support children receiving home care with community life" held a disaster prevention cultural festival for children who receive at-home care in February. The network aims to garner support from local residents by raising public awareness of children in the community who get special care at home.

Team Yachiyo Kids, a study group



Nachika Nishida, right, receives medical care from a nurse, front left, after returning from evacuee life to her home in Kumamoto.

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that looks at home medical care for children in Yachiyo, Chiba Prefecture, has drafted a booklet on key issues like securing a power supply for medical equipment and intends to deepen communications with each household.

Satoshi Takada, a professor at Kobe University and an expert on the support of children with disabilities and

their families, said that communities "need to strive to get into the habit of being aware of children who receive treatment at home since they'll be requiring special care during disasters."

"Preparations also need to be made so that each child can swiftly be provided with support that meets their individual needs," Takada added.